

Karen Staman and I met a while back through a National Institute of Health and Duke University research collaborative effort. She is a scientific writer by trade, which means she sits through lots of conversation and puts everyone else's thoughts into cohesive sentences that can then be published, and she understands science in a way so many of us don't.

At a quiet moment during our first day together, she shared with me that she also has MS, but had not told her employer or pretty much anyone else, other than her family and closest friends. We met at the hotel bar that night and discussed her treatments and her efforts to remain active in her favorite sport of rock climbing, and in chasing her pre-teen children through their routines.

We talked a long time, but I did not come away with the sense that she was considering taking the most dramatic step in stopping her MS — undergoing HSCT (Hematopoietic Stem Cell Transplantation). HSCT is a procedure where the doctors



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reboot your immune system by collecting some of your cells, then wiping out your immune system through the use of chemotherapy drugs and reintroducing your own healthy cells to rebuild your immune system. It is a much more complex process and commitment than I've given in these few words, and that is why I want to introduce you to Karen.

SUCCESS STORY, MS
and Night Shift
Work, MS
Biomarker Study

/ OCTOBER 21, 2019

It was only through later emails that her plan to go to Chicago for treatment with Dr. Richard Burt, Northwestern University, a pioneer researcher in the field of HSCT, was revealed. Karen took a number of big steps in this process, the first of which was to publicly announce that she has MS, and that she was going to try HSCT. I am sure it was not an easy decision, and not one she made without investigating further.

Karen did her own investigation, including accessing detailed journal articles about HSCT research, and came to the decision that even though HSCT was not yet an FDA-accepted procedure and still in the experimental stage for multiple sclerosis, she would pursue the opportunity to have it. Then she made her journey, that started in

autumn 2015, public through a blog,
[Karen Staman: *My Journey to Chicago to Get HSCT for MS.*](#)

Upfront, I must share that I am not in the camp that would do HSCT — to me, the evidence as to which stem cell procedure unlocks MS is just not there yet. Then there is the mortality rate that fluctuates as high as 1 in 200, depending on which batch of statistics you read. I am more cautious, and would like to see the reproducible scientific evidence before endorsing HSCT as the answer for thousands of people.

The uncertainty of HSCT was the agenda when an international group of researchers, including Dr. Burt, met in late 2015 in Portugal, to exclusively discuss stem cell research. The group's consensus, summarized on the National Multiple Sclerosis Society's site under the title "[Promoting Clinical Trials of Cell Therapy](#)," includes this information:

"Controlled clinical trials by investigators were deemed an optimal way to provide answers about which types of cells, which route of delivery, and which types and stages of disease, would be the

most promising approach for treating MS.

“A past roadblock has been that clinicians often use different treatment protocols, making it hard to compare results. Participants heard potential solutions to standardizing protocols and creating networks for centralizing data collection and analysis.

“There are outstanding questions about how to track transplanted cells within the body, how to determine if cell therapy is working, and ethical challenges for cell-based therapies, including the issue of patient-funded studies and the problems of unregulated [stem cell clinics](#).”

To summarize, the experts' recommendation is to do controlled stem cell clinical trials, with standardized protocol, in safe settings, and where they can gather consistent comparable evidence. The studies to date on HSCT have been observational ones, and not the gold standard model of randomized and controlled studies. Unfortunately, since Karen was not part of a trial for multiple sclerosis, none of her experiences count toward the body

of medical knowledge and, at best, is only compelling anecdotal evidence. I don't know if Dr. Burt is still accepting patients on a case-by-case basis if they don't meet the demanding criteria of the trials.

But this research approach — waiting for the research protocol to be designed — is not enough for many people like Karen, who feel the urgent need to seek treatment now. It has now been almost a year since this began for her and I wrote asking for an update. Was she feeling better? What was her outcome? I'm pleased to say she is feeling great and glad she had HSCT. But she also makes it very clear she didn't feel that way for a long time.

I asked if I might make her HSCT story public and share her blog link, and she was enthusiastic about this idea. I explained I have read numerous stories of people having HSCT and having these immediate miracle recoveries, which conjure up images of magic wands and unicorns, that I feel mislead people as to how "easy" HSCT might be. I know from discussions with people who have had this procedure, as well as a clinician who was a researcher on the [HALT-MS trial](#), an

earlier HSCT study, it doesn't work like that. The clinician said his patients in HALT-MS had such a rough first year he was sure they hated him, but then it got better in year two, and by year three they had forgiven him for all they went through. They were, for the most part, doing great. HALT-MS had a 70% success rate of sustaining improvement over five years, but that also means 30% of the participants did not benefit from HSCT.

I am also friends with a person from the HALT-MS trial who did not have permanent benefits from the stem cell treatment, but that's a story for another time.

If you have read this far, then you are really interested in HSCT and I know you will want to [read Karen's blog](#) about her past year and what she has gone through. It is a compelling story, and she spares none of the gruesome details of tests, and vomit, and lost hair, and questioning her decision. It is also full of acknowledgement that the words of encouragement and support from her friends and family helped her through the roughest days. I hope you will read Karen's story and return here to share your

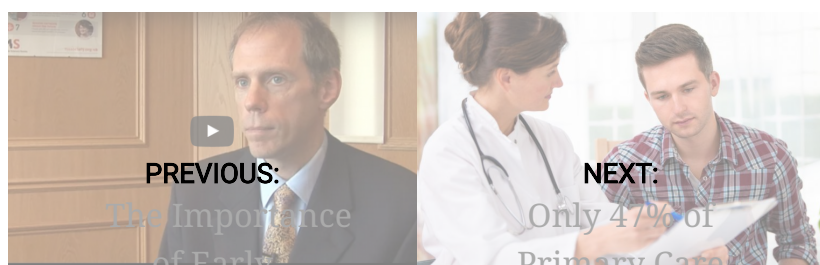
own thoughts after you have the chance to walk in her path through her writings.

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**Laura
Kolaczko
owski**

Laura Kolaczowski comes from Beavercreek, Ohio, and worked at the University of Dayton for over 25 years until MS challenged her enough to go onto full-time disability. She is active in the MS community on multiple levels, and writes for her own personal blog, InsideMyStory and as a patient expert for MultipleSclerosis.net. Laura is the Lead Patient Representative and co-principal investigator for iConquerMS™, a patient powered MS research network. Laura freely admits her Liberal Arts background fuels her interest in patient engagement and empowerment and she struggles with the science of MS.

TAGGED DR. BURT, HALT-MS, HCST, KAREN STAMAN, NORTHWESTERN UNIVERSITY, STEM CELL THERAPY.



Treatment in Multiple Sclerosis

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